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Deaf in the Family

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Deaf and Hard of Hearing in the Perspective of the Tradition,

Presence and Future

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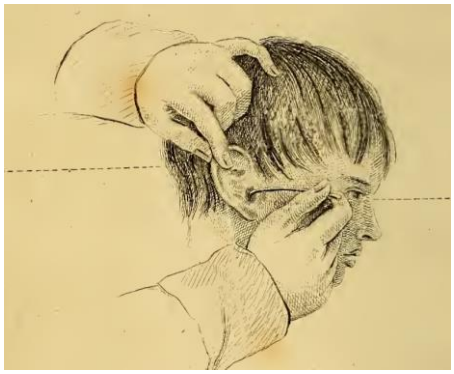
Abstract

Despite our 200 years (and more) of attention to deaf children, we continue to miss one most significant aspect of need. Although we work hard on deaf education to create citizenship, too often this is focused on making the deaf child normal and not on embracing diversity. We create layers of training and service provision: audiologists, speech therapists, teachers of deaf children, social workers and so on, but this only serves to confirm the child as the problem. We measure extent of hearing loss, assess competence of the child in terms of the expectations in education yet ignore the place of the child in the family. Our research work in Bristol over almost 40 years, convinces me that the interaction in the family is the most significant determinant of the child's adjustment to society.

In this presentation, I will examine family culture, its context, shared and negotiated aspirations and the skills the family needs in order to function optimally. We need to progress from early intervention and the provision of language in sign and speech, to recognition of the diversity of family structures. In examining this, I will draw on research on sign language acquisition, work with families at home before and during the school years, the resource that is the deaf community and on the contrast in discourse between the professionals we have trained and the families whom we seek to support.

Where we were in 1817

In 1817, in the UK, there was a major legal case in Edinburgh, which debated fitness to plead (in the case of Jean Campbell) accused of throwing her baby from a bridge. She was uneducated but the headmaster of the Edinburgh school was able to communicate with her and convince the court that she could go for trial. However, there was a great debate in legal circles about whether someone could be tried when they could not be questioned and they could not establish if she knew right from wrong. With the help of the head teacher of the school for deaf in Edinburgh, they were able to establish that there had been an accident and Jean Campbell was acquitted. The issues arising from the case are still not resolved in law.



In 1817, in Bristol there was no school, no service, but various fantastic cures for deafness. Books and adverts in the newspapers at the time explained how deafness could be cured with a little red pill.

I hope we have come a long way since then. And I congratulate you on your 200th birthday and on the large number of deaf people you have supported in that time.

Some of the changes we can point to since 1817,

- we can detect hearing loss almost at birth
- there are schools and services to support deaf children
- we know that sign language is a language; and exists in every country where deaf people are allowed to be together.
- there is general recognition that Sign Bilingualism is an effective approach – two languages are better than one

But along the way, something has been lost.

- Deaf children do not exist in a vacuum.
- They exist, grow and develop in a family.
- That family has a dynamic and …
- that family has its own distinct culture.

The relationships which constitute the family vary: single parent, parents and siblings (older and younger), extended family, socio-economic status and education. The hearing family in the video have a hearing son, deaf twins, and a third deaf child.

In the last year, I have worked closely with

- a family where both parents were deaf and their five children were deaf;
- another family where parents were hearing and older sibling was hearing but six year-old son was "deaf" with ANSD[1]

[1] Children with ANSD are likely to have greater difficulty understanding speech and distinguishing one sound from another than a child with a similar level of hearing, especially when there is

- another family were refugees from Iraq; hearing mother, father and older brother, but deaf 6 year-old. No knowledge of English and never had access to pre-school support. The boy was learning to sign but the family were not.

Families vary, their expectations and understandings vary, their capacities to manage the changes when there is a deaf child; and most significantly, their "family cultures" are extraordinarily varied.

Services to deaf children

We have seen enormous changes in our approach to deaf children since I first began work. At that time, deaf children were handicapped children with poor cognition. In the mid 1970s they became "children with special needs", which in turn led then to a programme of integration and closure of separate deaf schools in the 1980s and then culminating in the Salamanca Statement[2] in 1994. This evolution produced the concept of services for deaf children.

However, in the last 15 years, even this has changed.

Nowadays in the UK, the expectation is that families should not only be central to decisions about their own child but should also be empowered to contribute to the shaping of whole services. The Children's NSF Standard 8, (Oct 2004) set a vision: to see children and young people and their families actively involved in all decisions involving them and in shaping local services. This message is continued in *Every parent matters* (2007), which says that engaging parents effectively means giving them the means to influence the shape of services.

The Parental Involvement in Commissioning initiative (http://www.dcsf.gov.uk/everychildmatters/strategy/parents/pip/PIPrkparentalinvolvementcommissioning/PIPparentalinvolvementcommissioning) sets out clearly a matrix of involvement (Figure 1)

Figure 1 Parental Participation

Parental Participation in Commissioning Matrix

Level of involvement

	Information	Consultation	Participation	Partnership	Delegated control
Governance		Meetings with Children and Young People's Partnership (CYPSP) board (advisory)	Shadow parent board Parent(s) on CYPSP Board		Devolved budget to parent group
Analysis	Presentations and reports on needs and research findings made available to parents Newsletter	Service evaluations, focus groups discussions with parent forum satisfaction surveys re. current services Complaints monitoring	Parents on steering groups		
Service design and strategic development	Commissioning plans made available to parents	Representative groups invited to comment on service design Telephone surveys	Ongoing parent panels to agree proposals parent reps on planning groups	Equal partners on strategic planning and service design groups Engage with parent organisations and support groups	
Tendering	Parents informed once contract awarded			Parents on evaluation panel for awarding contracts	Parent run services
Service monitoring		User feedback on satisfaction with services through questionnaires, panels	Ongoing parent panels for reviewing services and interpreting feedback	Parents design performance management arrangements	

background noise. They hear 'sounds' but with distortion.

[2] http://www.unesco.org/education/pdf/SALAMA_E.PDF

This is highly ambitious and puts parents (and family) at the centre of the process. The highest level of involvement implies delegating the budgetary control to parent groups, who would run the services. The principle is forward looking but the implementation is still pending.

Typically, parents are unfamiliar with the problems they are to face as the child grows and are usually unprepared for the impact of a new deaf baby on their existing family and their already established lifestyle. While promoting family decision-making, service professionals have also to act as an information resource and support to the parents – for some, they may be the only source of information. The extent to which that support is *guidance* rather than *counselling* and the extent to which the Education's Authority's existing provision, finances and philosophy act to narrow the choices for families and thereby the amount of information supplied, is not well explained.

Parents are expected to exercise informed choice and this is likely to provoke a series of reactions. On the one hand there may be dismay, disappointment, recrimination at the discovery of hearing loss in the child, while on the other hand there will be commitment to change and active search for solutions as the child is accepted into the family.

Our definition of 'Family-led' where the control and decision-making on the support and interventions for any member of that family are determined by the family itself and not just 'provided', appears in the literature relatively rarely. In most models, parents are meant to be recipients of services designed by experts to support the family in managing a disability. Although there is usually a process of consultation, the reality is that parents are expected to acknowledge and accept the problem/difference (on behalf of their child) and to embrace the service concept before services are to be provided.

Many publications use the term family-led when in fact what is meant is the scenario where professionals are working with family groups in a leadership or guidance role. The families while nominally the decision-makers may not have access to independent advice (i.e. separate from local authorities or suppliers) and may find the extent of the professional training of their advisers both a help and an obstacle.

Reflecting on Deaf Family involvement

In this context, an account by a parent of his family experiences with the education authorities and school is of some interest. Mowl in 1996 describes his interactions and concerns about the education that his Deaf children received. Although this case refers to the United States, the nature of the Deaf family i.e. two parents who are deaf using American Sign Language and two children who are also deaf, informs our discussion here.

The Mowl family were very pleased to have healthy deaf children but,

> "We never expected or dreamed that their being Deaf would pose additional issues for us as parents that would consume time and energy. But we found that the external forces of the society are so powerful that we must constantly address the issue of their being deaf, which to us, is a non-issue." (p 234)

He considers that social pressures and in this case educational pressures were so strong and negative as to provoke anger.

> "This is the real world… In this debate the term 'the real world' has been used in a variety of contexts in discussing why ASL may hinder the functioning of deaf persons as members of our society. When establishing educational expectations for our children, great value has been placed on preparing them for 'the real world'.
> We have often wondered: what is this 'real world'? Whose world is it? By whose standards? Who should define 'real world' if such a definition is needed? Apparently a real world has been defined for our children. For the education of our Deaf children the real world is defined by our school district led by a team of special educators who shape educational plans for our children.… This implied to me that these special educators with no experience of growing up Deaf, think they understand the education of Deaf children and are able to assess our children to figure what the future holds for them in this world." (p 235)

We can see the frustration and anger in this situation – precisely the same issues that arose with my case of the deaf family with five deaf children.

Meetings involving the Mowl family were often protracted affairs.

> "Brenda and I are stubborn. We had a meeting once that lasted four hours. We have a reputation of being difficult. We have had and still do have conflict with the team on issues of how educational plans are to be devised to help our children prepare for the real world…. We do not see eye to eye on many issues but they do not seem to be bothered by that."

The Mowl family were continuously having difficulties with the school over different aspects of the education and particularly of the assessments of the child. They were unhappy that their child was taken out of certain classes in order to have speech teaching. They objected to this and asked for speech training (which they considered to be important) to take place either before or after school. However, they were told that it had to be during teaching hours because the speech teacher would only work during the class hours.

> "Speech instruction of course is important but at what cost? Speech or English? Speech or maths? Speech or science? Speech or physical education? Our choice was quite simple: the goal of education for our children in our opinion, should be to maximise their intellectual abilities, to develop their character and to give them an appreciation of the society at large" (p 241)

As we read this account we get a much clearer insight into the thinking of a *normal* Deaf family in contact with those who provide education for their children and particularly, education in a mainstream setting. Awareness of their feelings and of the advantages which their involvement might offer is of considerable importance in what is almost certainly the shared objective of maximising the potential of the children.

Hearing families with deaf children at discovery

Nowadays, we screen children at birth to determine whether they have a hearing loss. After the joy and pain of childbirth, parents may be faced with the discovery that the child is deaf. Alys Young in several articles (eg 2010) has examined this early period of discovery and explains some of the vulnerabilities for families in this time.

Although there is a general professional view that early diagnosis is beneficial for the deaf child, there has been little attention to the impact of early discovery on the development of the family's relationship with the new baby. While, with later diagnosis, families have the chance to be part of the process as they adjust to, and notice, the child's hearing loss, with early screening, the discovery is set wholly within a medical context and without any parental consent or engagement. Families find out about deafness in a medical setting.

Some researchers have argued that this early diagnosis forces parents to focus on the child's impairment and not on the development which will normally occur in the first year. One danger of this is that the service pressures the parents to focus on speech alone and does not recognise the significance of sign language communication. The discourse of early diagnosis focuses on speech and hearing.

Hearing families with Deaf children as they grow

Our approach (in Bristol) to this has been to put in the forefront, the existence of and the development of family relations. We worked with parents, ran workshops, offered support in interaction and specifically introduced deaf adults into the engagement. Recently, the early diagnosis and the medical incentive to have cochlear implants, has weakened the bilingual principles of the programme, in the minds of the service providers.

Our research study in 2009 (Stepping Stones) contrasted the experiences and views of parents with those of the professionals who were delivering the service. A parent of a deaf child was the researcher who interviewed other parents, while an education professional interviewed teachers and audiologists. What follows is drawn from the data in that study.

A common assumption that there exist 'families of deaf children' as a group turned out to be incorrect. Parents brought together by service provision for their deaf children, are unlikely to share any life interests or common ground … other than that their children have a hearing loss. It is unlikely that a 19 year-old unmarried mother would share a great deal with a solicitor-teacher couple who just happen to have a deaf child of the same age. Yet it is a common concept expressed by service providers that 'parents of deaf children need x and should do y'. We found that some parents were overawed by the professional interventions while others wanted a more direct, meaningful involvement – a share in the power.

The notion that parents ought to be available at all times to support their children was also challenged by the reality of family life – which simply did not allow the parents time to attend hospital, meetings, learning sessions and be able to take the lead in working with other parents. Many were uncomfortable in expressing their views in public groups and would not necessarily have management skills to take part in a family-led initiative.

Existing consultation methods with parents (eg Working Groups) were seen as "talking shops" ie lacking power for change, by those parents who actually knew what they were (the minority). Typically, parents believed they were offered services which already existed and not given the opportunity and time to express their own needs as a family.

While promoting family decision-making, service professionals have also to act as an information resource and support to the parents – for some, they may be the only source of information. The extent to which that support is guidance rather than counselling and the extent to which the Education Authority's existing provision, finances and philosophy act to narrow the choices for families and thereby the amount of information supplied, is not well

explained. Realistically, support begins from the *existing* network of provision in each service.

Our definition of 'Family-led' where the control and decision-making on the support and interventions for any member of that family are determined by the family itself and not just 'provided' appears in the literature relatively rarely. In most models, parents are meant to be recipients of services designed by experts to support the family in managing a disability. Although there is usually a process of consultation, the reality is that parents are expected to acknowledge and accept the problem/difference (on behalf of their child) and to embrace the service concept or else no service will be provided.

Many publications use the term family-led when in fact what is meant is that professionals are working with family groups in a leadership or guidance role. The families while nominally the decision-makers may not have access to independent advice (i.e. separate from local authorities or suppliers) and may find the extent of the professional training of their advisers both a help and an obstacle.

In our study, here are some of the factors which parents were concerned about.

Allocation and use of time

A great deal of time is spent in appointments that parents have to attend about their deaf child. For those parents who live further away from those appointments, a great deal of time is used while travelling. For some parents, it is just impossible.

Managing the responsibilities and information

The parents have a lot to take on board. The required shift in perspective (concerning their children) is a challenge. This shift involves many appointments and a change in language. It is difficult to discuss the issues with friends who do not have a Deaf child.

The Bridge for the Child

The parent has to act as interpreter for her child. The parent feels like she/he is always 'on duty' in support of the child. She/he has to be the link to other people and to the world's experiences.

Managing other people's reactions

Coping with *other* people's embarrassment about being with a Deaf child is an issue. The reaction of others can be a major problem and often the responsibility for resolving confusion or embarrassment rests with the parent.

Community of Parents

In terms of community-building opportunities, parents meet together because they have a Deaf child, not for any other reason. The Deaf child is the link. The community is *imagined*. Many barriers would need to be broken down to create a real community.

Community of Deaf children

A community of Deaf children is not automatically created either. Geographical isolation (even in cities) can be a huge issue for Deaf children. For many Deaf children social skills are not well developed; they do not always relate to one another naturally and effectively.

Learning Sign Language

There are enormous barriers to parents when they are learning sign language. These include access to class and the cost of the classes. Most classes are not appropriate to family life interactions. The functional family-centred signing that they need is seldom offered.

Mother as caregiver

Often it is the mother who is the primary care giver, gatekeeper and manager. This places particular strains on the mother and upsets the usual balance of power and relationship in the family. It may be particularly an issue when there are other hearing children.

Fathers' role undermined

One of the results is that the father feels remote from the relationship with the child and with the process which surrounds the child. Rarely are there support groups for fathers. This alters the structure of interaction in the family. It is also likely to mean that fathers are not as skilled at communicating with the child.

Parent Resource and Self-confidence

When parents meet they may feel under pressure to present themselves in a good light. This may be psychological in terms of confidence and ability to speak out in groups but it may also be real in socio-economic and practical terms – e.g. having a car to attend the meetings in the first place. Parents' groups are diverse in these terms. There may also be differences in terms of the situation of parents. For example, parents with a Deaf child with learning difficulties who has no friends, may have difficulties in discussion with other parents. There may also be a need to put on a brave face; for example a mother who was brought up in-care will be reluctant to say that she can't cope because she has a fear that her child may be taken away from her. As a result of these pressures, parents may need to create a 'front' in contact with other parents. Attending a parent group may not be easy for some parents.

Professionals – teachers, doctors, speech therapists

When a child receives a review of his provision, the professionals have to observe the child and give their opinions. Many professionals are not able to use sign language and as a result the review is likely to be incomplete and even inaccurate. What is needed in those cases, is a professional who is able to sign (or a Deaf assessor).

Involvement of Deaf Adults

One project that seems to work is based in Bristol. It is called Deaf Children at Home. This involves a Deaf adult coming to the family and working with the Deaf child. This was not automatically offered nor was it available in other regions.

Information Provision

It was felt that the provision of information is variable. It is not automatically provided for families and this can cause problems for the family.

Perspectives of those professionals who work with Deaf children

Most of our interviewees worked with young children and their families. From a preliminary consideration of the data and the contacts made, it seems clear that the infrastructure for family related services are focused primarily on younger age children

How the professionals support and guide Deaf children and their families

Family support was usually set up through meetings and discussion groups. Such sessions were meant to be family-centred even though they might not be family-led.

There were a variety of groups for families and their children. As a rule these were mainly opportunities for parents with young children to meet. There were groups for parents with Deaf babies, with Deaf toddlers and children up to school starting age. The school worked with youngsters and their parents at the primary stage.

The health professionals talked of how to support children attending their clinics; the needs tended to be seen in the same area as in the provision of diagnostic tests on babies and children, and evaluating and monitoring hearing aids.

The concern of the health professionals who work with these families was mainly limited to audiology and spoken language.

Current means of monitoring and evaluating the service

In order to determine the success of the programmes, the education services staff reported the use of questionnaires for parents and exam results for children. They also mentioned the use of Early Support materials. One Head Teacher reported a range of methods:

> OFSTED self evaluation framework Local authority. There are 3 core visits a year which include: Child attainment and achievement Quality of provision Leadership and management Pupil and parental feed back We are continually evaluating ourselves (Head teacher of school for Deaf children)

With older Deaf children examination results are included in the evaluation and there is a self evaluation framework within family sessions. It is not clear if these evaluations are shared with other families or whether there is family specific evaluation.

The health professionals talked of the use of systems to monitor service. A major component of this is a system of Quality Assurance teams visiting and running comprehensive evaluations against a range of quality standards. Reports are written and published on their website. Improvement plans are set out and sites are re-visited at a later date to ensure relevant actions have taken place.

The services that are available for families are said to be offered in a fluid and responsive mode; but it seems that objective family-centred evaluation is limited (it is only a part of the way in which services are constructed – being more likely to be driven by the person with the identified problem).

The role of sign language

In some of the education services, BSL is present and is discussed by staff. There are Deaf workers who will sign to children and families during family sessions. In the Bristol area, Deaf workers will also go to families' homes to communicate with the children and to teach parents how to sign. Staff, including administrative staff, will have experienced at least some of the stages in sign language training. It is a goal that people working with Deaf children will have completed stage 3 of the national sign language training framework although for the administrative staff this would not necessarily be the case.

The health professionals do not generally use sign language, but may have access to interpreters. There is not a sense of this being a major agenda item and it seems likely that the approach to hearing loss places sign language users as very much a minority in the whole client group.

Initiatives that are currently in place for families with Deaf children

There appear to be variations in service initiatives which is considered to be responsive to the particular groups who are present at that time.

> Groups change so the population changes. On occasions parents mainly have very young babies and at other times they mainly have older children. Some families decide not to attend. The reasons include 1. transport, 2. culture, 3. language. Some families do not want to be seen as deaf. (Head of sensory support service)

The lead in initiatives for families were usually on the professional side. The take up for these initiatives varies. For example, in one town which supports Deaf children from a number of local authorities in the education of their child, it was said that approximately 35% to 40% of families take part in family groups. A health professional commented:

> This (use of family groups) seems to move in waves. Some families don't want to attend. Social class differences can cause difficulties. There is a very small ethnic minority. There are some Polish and Portuguese families for whom it is difficult to get interpreters. (Team leader and local coordinator of NHSP)

The professional view seems to be that there are fewer parents able/willing to take part in group sessions than we discovered when talking directly to the parents.

How families are involved in decision-making with regard to services

Commonly the professionals mentioned the working groups as a means of involving families in decisions, although it was not made clear how this would enable parents to be involved in *decision-<u>making</u>*. Parents did not feel they affected decision-making.

Particular issues raised by working with the families

For much of the time, service professionals work with the child and so it may not be obvious which issues relate to the *family* itself. Typically, the responses referred to parents rather than families.

> Parents report feelings of being overwhelmed by professionals. This is made more difficult when parents are resistant to results. (Paediatric audiologist)

Confidentiality

Another common view is that when working with families, confidentiality is of primary importance. We found this became a reason for not putting parents directly in touch with each other. It had also a further twist in terms of the ownership of the information in that one of the health professionals said she thought it was great that parents would have access to a wide range of provision but the information would need to be given by professionals. The view was that for some parents, the information could be overwhelming and professionals would need to choose the best times for information giving.

Contrasting views on Parents and Professionals

Our study showed very clearly the different discourse of professions and the service-speak and provision-led processes. Much of this is alien to parents. But also, irrelevant to the concerns of everyday life.

In England, only 15% of the child's waking hours are spent in school. Yet most of the service input and expenditure is focused on the contact between professionals and child (sometimes with parents). We point this out to parents, encouraging them to be confident in their own knowledge and in particular to be strong in enabling their own cultural expectations and experiences.

Family Culture

One final aspect to discuss is what we have come to think of as "Family Culture". This was first proposed in this context by Flo Canavan, a Bristol graduate student researching sign bilingualism in the home and the relationships with the deaf community.

Her view developed from interviews with parents, was that families existed (usually) prior to the birth of the deaf child. They had routines, ways of thinking about their lives and plans for now and for the future. In most families, culture is transmitted from parents to child as expectations and ways of behaving. When hearing children precede the birth of a deaf child, such culture is well established.

Discovery of deafness in the infant in a medical context, disempowers the parents almost immediately. Service provision soon after birth focuses on what the child is thought to have lost and parents are lured into the programme of trying to replace what might be lost. And this is typically the apparent need to ensure speech competence.

In our work, we offer a more positive view of the child, as a functioning, able member of the family, who will contribute to the family culture and for whom it is worth making the adjustments. Not surprisingly, we promote sign bilingualism as an effective strategy, no matter the "measured hearing loss" and even if the child has a cochlear implant. Two languages ae better than one.

At the same time, we acknowledge the family context, the particular skills and expectations of the parents and the way in which they expect to organise their lives.

Contact with deaf adults is vital to gain perspective and recommendations after the family assessments we carry out, almost always recommend regular and continuing contact with deaf adults… for the child, but also for the family and in the home.

Conclusions

I will finish with reference to two videos which I have shown many times. They show a 2 year-old deaf child interacting with her mother and a deaf researcher and then interacting with her father. She is still a learner of sign language, as are her parents.

She is normal. She is inventive in her signing, albeit not fully comprehending others. Her father while having learned sign does not yet apply it appropriately. The family is already bilingual in spoken languages and they see no difficulty in introducing a signed language. The recordings were some years ago. The child has now become a bilingual woman and a university graduate.

The point is that we need to understand and work with the families in action, at home. We need to explore and share their expectations and adapt to family functioning and not focus solely on professional contact time with the child.

We can be positive about the family's culture, about their capacity to engage with the child and their other children.

And we need to have our programmes reflect this sensitivity to family life.